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So You Want to Start a Patient 'Policy Panel'

Communication | Editorial | **Invited contribution** | Perspective | Report | Review

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Following some time in research, I put down my pipettes to join Blood Cancer UK as a Policy Officer. Blood Cancer UK is a medium-sized charity that funds research and provides information, support, and advocacy to those affected by its namesake. The charity aims to put people affected by blood cancer at the centre of its work. This is easy (and increasingly popular) to say, but harder to do. Recognising that our policy work often lacked patient insight, I established a 'Policy Panel' (see Box 1). New to the acronym-dense policy world, below are some of the lessons I learned setting up and managing the Panel, and advice[1] for those considering a similar group.

> Box 1: About the Policy Panel
> Composed of ∼20 individuals from across England with personal experience of blood cancer, the Blood Cancer UK Policy Panel was established to provide insight and direction to the organisation's policy work, and to ensure its work to influence the health policy agenda reflects the community's priorities. In addition to providing ad hoc input to the charity's work via telephone and email, Panel members regularly participate in NHS, government, and parliamentary events to ensure blood cancer is well represented, and that the issues affecting patients are understood by decision makers. Twice a year, the group additionally meets in person (via videoconferencing at present due to COVID-19 restrictions) to explore pertinent blood cancer policy issues in detail.

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Descriptive, Not Prescriptive

Patient and Public Involvement (PPI) can deliver multiple benefits to organisations but is all too often a poorly thought through 'tick-box' exercise. In designing your group, consider what value PPI could add to *your* activities and work backwards from there. Draft a clear Terms of Reference (ToR) describing your group's purpose, what will be asked of members, and how you will work together, etc. Once your group has been established, communicate frequently, openly, and in plain English.

That being said, be flexible where possible. In drafting your ToR, you described in detail what your group will and will not do – perhaps you were a little *too* prescriptive? Your group is composed of knowledgeable and passionate in-

[1] See final section 'Disclaimer and Final Reflections'.

dividuals. In policy, things move gradually, then suddenly. When unexpected influencing opportunities arise, consider whether your group can play a role in campaigning for change.

(Re)set Expectations

To the uninitiated, it's clear that in a given charity, the support team supports, the fundraising team fundraises, and the policy team... does something in Westminster? Policy is a nebulous word. It is therefore important to set clear and realistic expectations to your new group – explain what policy is, what it can achieve, and the pace it moves at.

Furthermore, often driven by a poor personal experience with their treatment or care, many applicants to your group will do so seeking to campaign passionately for a particular change. With limited capacity (and budget) it is important that you are clear which issues your group will focus on. This will manage expectations and avoid potential later frustration.

Reflect Your Community

Health inequalities in the UK are multidimensional and widening. It is therefore important that your group is reflective of the community it purports to represent in terms of age, gender, ethnicity, and multiple other characteristics. Although blood cancer affects all demographics, it will surprise few in the charity sector that the majority of initial applicants to the Blood Cancer UK Policy Panel were white, female, older, and from the South East of England. To ensure a more representative Panel, we actively sought applicants from under-represented groups; working closely with cancer Clinical Nurse Specialists 'on the wards' and blood cancer organisations primarily serving minority ethnic communities.

When arranging meetings, it is important to remember that while you will likely be travelling via the Central Line and paid for the pleasure(!), your group will be travelling from across the country – voluntarily. Increase accessibility, particularly to those less affluent or residing outside of London by covering expenses in full.

Proper Prior Planning...

Meet regularly but never for the sake of meeting. Consider what aspects of your work could be furthered by having your group together for an extended period of time (to provide insight to your work; to sense-check your tentative policy recommendations; to discuss an emerging issue?) and format your meeting accordingly.

Always consider the needs of your group and their 'user experience'. If performing work on a topic, particularly where complicated or technical, consider providing a briefing beforehand to ensure everyone has a sufficient understanding to contribute to a discussion. Remember that you are working with real people with busy lives: give dates well in advance as well as an agenda and an abundance of practical details – not just where to meet but how to get there as well.

Trust Your Group (But Also Yourself)

Your group are experts by experience. You can analyse all the NHS statistics available, but only a patient can describe what their late diagnosis *felt* like. Frequently, the NHS, research centres, and similar organisations seek the '*[insert-disease-name-here]-perspective*' to inform their work. What is typically being sought here is not a PPE graduate with an encyclopaedic knowledge of NICE guidance, but a genuine patient voice. Through working together closely over time, your professional recommendations will increasingly mirror your group's. Simultaneously, your individual group members will become better able to provide perspectives broader than their own, and can attend events independently to represent their wider community (additionally increasing your reach and capacity).

However, you *are* the person being paid to analyse the NHS statistics and who understands the intricacies of the broader health policy landscape. Allow your group to inform and influence your policy recommendations (lobbyist, lobby thyself!) but not to determine them for you. Although admittedly tempting to accept recommendations from your group members wholesale – especially

when pushed for time or capacity – it is important to objectively evaluate each recommendation; even if borne out of personal experience or perfectly formatted to slot into a workshop or ongoing inquiry.

Sell, Sell, Sell

Your group is wonderful – so talk about it publicly and at every opportunity. The benefits are two-fold: your organisation's supporters will be pleased to see the important work you are doing in conjunction with members of their community, and decision makers will be more likely to proactively approach you with influencing opportunities due to your unique resource.

But also use your group to create *new* opportunities. For example, while you may have previously found the minister unable to meet due to severe diary pressures (read: you are one of N groups seeking to introduce a subject to the medical school curriculum), offering to meet with a representative group of patients often results in time being found. There is power in numbers and a person's story is almost always more captivating than a cost-benefit analysis.

Disclaimer and Final Reflections

Patient and public involvement varies greatly between sectors and organisations. Above are my personal reflections, written from the narrow perspective of someone new to policy, working in one such sector, for one such organisation – ensure that your group is appropriate for your organisation and the landscape in which it operates.

Measuring impact in policy is challenging – a lever pulled in one area often brings about change in another, months or even years later. Regardless of the metric applied, my team can point to numerous successes: evidence submitted to parliamentary inquiries; new drugs available on the NHS; meetings with government ministers. Many of these achievements were aided by the Blood Cancer UK Policy Panel; some were only made possible by the group. My thanks to all members for their engagement, hard work, and friendship.

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Conflict of interest The Author declares no conflict of interest.